

ADVOCACY ACROSS THE LIFE COURSE

A Guide to Systems Advocacy in the District of Columbia for People with Intellectual and Developmental Disabilities and their Families



This Guide was created through the District of Columbia Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities (CoP). The DC CoP partners include the DC Department on Disability Services, DC Developmental Disabilities Council, Project ACTION!, Advocates for Justice and Education, Georgetown University Center for Child and Human Development, Health Services for Children with Special Needs, Inc., and the Quality Trust for Individuals with Disabilities. This project is funded by the Administration on Intellectual and Developmental Disabilities and is managed by a partnership between the National Association of State Directors of Developmental Disabilities Services (NASDDDS), University of Missouri Kansas City Institute for Human Development (UMKC-IHD), Human Services Research Institute (HSRI), and the National Association of Councils on Developmental Disabilities (NACDD). Significant contributions to this Guide were also made by students with The Community Justice Project at Georgetown Law School.



**Community of Practice
for Supporting Families of Individuals
with Intellectual & Developmental Disabilities**



Table of Contents

Introduction to the Community of Practice	4
Introduction to the Advocacy Guide.....	6
Levels of Change.....	7
Level One Changes - Individual	7
Level Two Changes - Organization.....	7
Level Three Changes - System	7
Overview of Budget and Legislative Processes	9
DC Oversight and Budget Process	9
How a Bill Becomes a Law.....	10
Advocacy at each Life Course Stage	11
Prenatal/Infancy	12
Early Childhood.....	13
School Age.....	15
Transition	17
Adulthood	19
Aging	20
Case Study: Ending Commitment in DC.....	21
Conclusion.....	27
Appendix	28

Introduction to the Community of Practice

There's no greater champion for justice and inclusion for people with disabilities than people with disabilities themselves and their family members! In DC, the Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities (CoP) is a group of family members, government leaders, advocates with disabilities, disability advocacy and services professionals, and other interested community members who are thinking together about how to create policies, practices and systems that better support families that include a member with an intellectual or developmental disability across the life course.

Definitions of Intellectual Disability and Developmental Disability:

According to the American Association on Intellectual and Developmental Disabilities, intellectual disability is defined by significant limitations in intellectual functioning (reasoning, learning, problem solving) and adaptive behavior, which covers a range of social and practical skills and originates before the age of 18. A developmental disability is an umbrella term that includes intellectual disability but also includes other disabilities that are severe chronic disabilities that can be cognitive, physical or both and that appear before age 22 and are likely to be lifelong.

DC has a unique opportunity as one of five states awarded a grant from the Administration on Intellectual and Developmental Disabilities (AIDD) to create a CoP for identifying ideas and changes that can be made to the systems that support people with disabilities and their families. The National CoP includes DC, Connecticut, Oklahoma, Tennessee and Washington, as well as the mentoring state, Missouri. More information about the National CoP can be found on the web at <http://supportstofamilies.org/cop/>.

Advocacy:

any action that speaks in favor or, recommends, argues for a cause, supports or defends, or pleads on behalf of others.



Life Course Framework:

A structure to help people with disabilities and their family members think about their lives. The structure allows families to focus on each life stage, while also keeping a vision for the future.

The idea to create this Advocacy Guide (“Guide”) was born out of discussions with the DC CoP and it has been developed by people with disabilities, their family members and advocates to help people participate in advocacy that will change systems for lots of people in DC, not just one person or one family. Following lessons learned by the National CoP, this Guide will use a life course framework to talk about needs and opportunities for advocacy at different stages of life. Each life course stage has unique meaning for each of us and each decision affects each person’s journey toward their goals and dreams.

The DC CoP has identified an important tool for advocacy called a one-page profile.¹ The one-page profile (included in the Appendix) can be used by people, families and other groups as a way to guide person centered thinking practices and bring a human face to every conversation about services, supports, policies and practices, which is a necessary aspect of advocacy! The CoP has identified a variety of ways to use this tool in advocacy, including the following:

- To train support staff so that they are able to see the person they are serving as someone with skills and talents who deserves quality, person-centered support
- To use during testimony in front of Council of DC so that Councilmembers can know the people who are affected by their decisions
- To use as an opening agenda item for an Individualized Education Plan (IEP) or Individualized Service Plan (ISP) meeting so that all meetings start out on a positive note and are focused on the talents, skills and needs of the person receiving the service



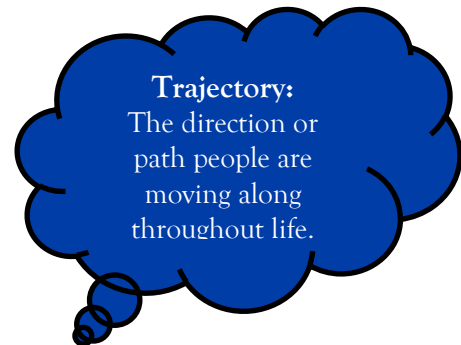
Person Centered:

The idea that the things that are important TO a person, those things that bring them happiness, comfort and satisfaction, are equally important to the issues of health and safety that are important FOR the person. Person centered services support people to find the right balance between what is important to them and for them, to have positive control over their lives and offer an ongoing commitment to each person to listen, learn and take action based on that learning.

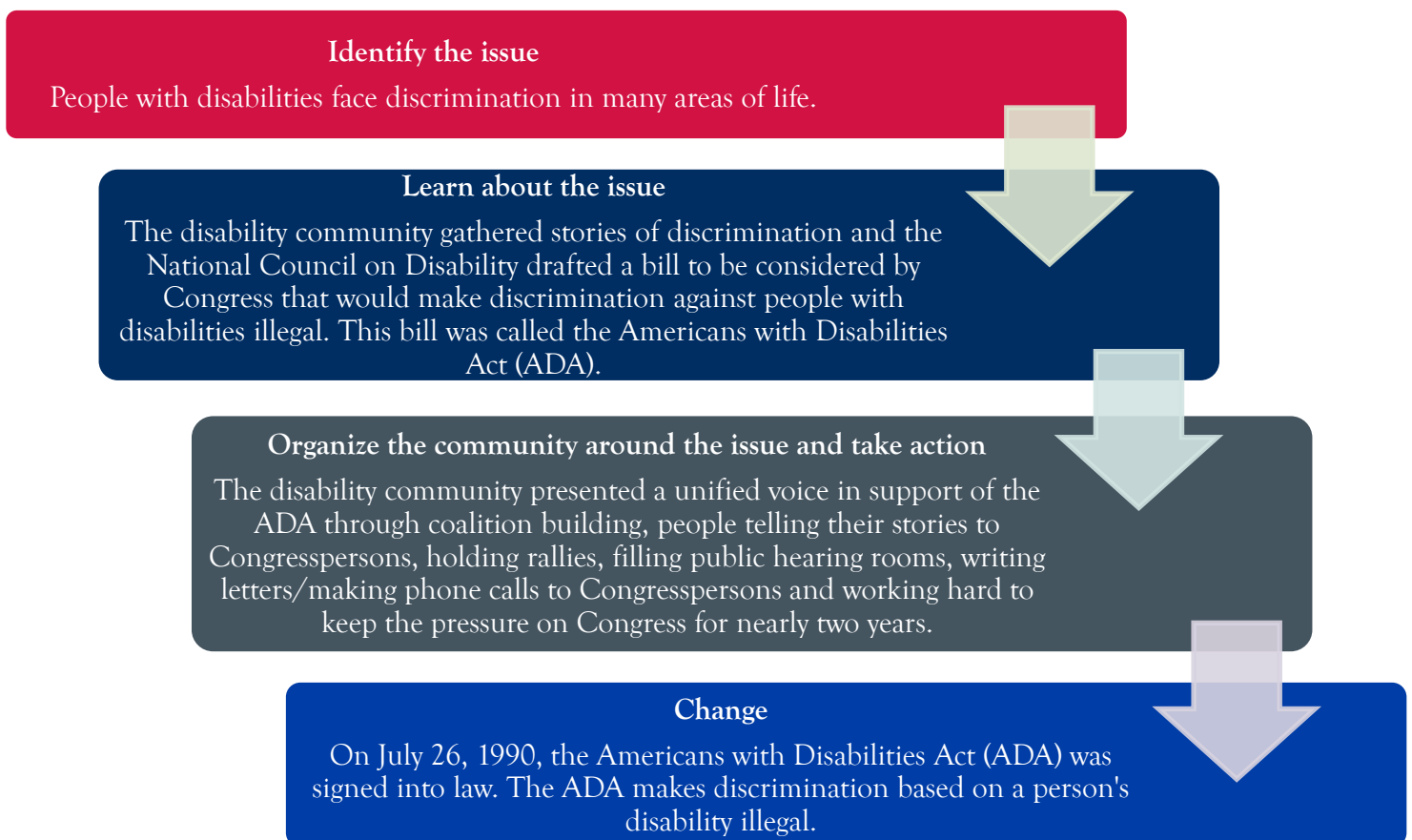
¹ The concept and design of the one-page profile is courtesy of The Learning Community for Person Centered Practices ©.

Introduction to the Advocacy Guide

Throughout the life course, our lives are impacted by actions we take and that others take on our behalf or in an effort to change systems. In each stage of the life course, those actions can change the trajectory of our lives. At times, we may run into barriers to achieving the vision we have for ourselves and our family members. It is when we encounter those barriers that we turn to advocacy.



Advocacy can involve many things. The example below shows the basic process of advocacy followed by the disability community in the 1980's, leading up to the passage of the Americans with Disabilities Act.



Levels of Change

As we journey through life, we all make changes in an effort to get the things that are important to us in our lives. Sometimes these changes are minor, like trying a cup of sleepy-time tea before going to bed to see if it helps us sleep better. Other times, the changes are bigger, like buying a home to make room for a growing family. In thinking about these different kinds of change, we can identify three specific levels of change that will help us understand what we, as individuals, are in control of and when we need to engage in advocacy to get the change that we need for ourselves or our family members to thrive.²

Level 1 Changes - Individual

Definition: Any change that can happen within existing regulations, policies and procedures that results in a positive difference in one person or one family's life.

What to do: Learn about existing regulations, policies and procedures and identify things that can be changed based on what is important to people who receive support. Identify areas where change can happen without permission from a supervisor or administrator of the service system and act on those areas.

Who can do it: People receiving support, family members, teachers, direct support staff

Examples: At Ebony's annual ISP meeting, her mother advocates that the team include a goal related to finding a job working with animals. Ebony has expressed an interest in working and she loves animals, but an employment goal was not previously part of her ISP.

Level 2 Changes - Organization

Definition: Any changes an organization makes to its practices, structure or procedures that result in positive differences in the lives of people.

What to do: Alter and implement changes to policy, practice, structure, rules, organizational culture, standards or requirements as needed to create a person-centered organization.

Who can do it: Service provider agency directors, service provider managers

Examples: A middle school begins an initiative that will support all students with IEPs to learn how to lead their own IEP meetings. Previously, middle school staff led the meetings.

Level 3 Changes - System

Definition: Any change in laws, regulations or structures made at the larger system level. These changes have an effect on many organizations, and therefore many peoples' lives.

² Information and graphics on Levels of Change are courtesy of Support Development Associates ©.

What to do: Collaborate with state agencies, policy makers, and elected officials to make the necessary changes in policy, laws, regulations, practice, infrastructure, or rules which impact people's lives.

Who can do it: DC agency directors, the Mayor, DC Councilmembers,

Examples:

- Families advocate with DDS, the Department of Health Care Finance (DHCF) and the Mayor's Office so that family members of adults with intellectual disabilities who live in their own homes can work as Direct Support Professionals and be paid for providing care to their adult children or siblings. DDS and DHCF agree to change the regulations and allow family members to work as paid caregivers.
- DDS changes all policies, procedures, regulations and communications to use person-first language after advocates with disabilities advocated for this change.
- Families of people with developmental disabilities, like Autism, identified the need for a change in law to expand the eligibility requirements for DDS services to cover more people and are advocating for that change.
- The disability community will advocate for an increased budget for DDS so that it has the funds to serve additional people who will be eligible for services once the change in law is successfully carried out.

The three levels of change all feed into one another. People and organizations make the changes they can make and if they run into barriers, those barriers inform advocacy for level three changes. Level three changes enable organizations and individuals to make more changes, all in an effort to support people in having the lives they want.

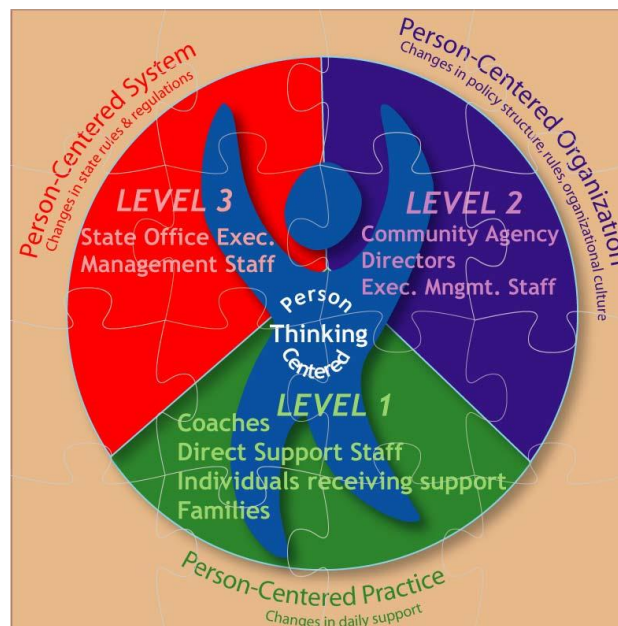


Image Description 1: Pie chart showing Levels 1, 2 and 3 change of person centered thinking. The image conveys the differences between these levels as described in the text and implies that that they are all pieces working together to make a whole.

Overview of Budget and Legislative Processes

Understanding the basics about how the DC government passes laws and makes decisions about the DC budget is important for being successful at advocacy. These processes can be confusing at times, but remember there are many people and organizations that have experience with this work that can help! The Appendix of this Guide includes resources that will help people navigate the budget and legislative processes.

DC Oversight and Budget Process

Each year, the Council holds public hearings with DC government agencies to carry out performance and budget oversight. The Council is divided into committees and each committee holds one performance and one budget hearing for each agency it oversees. The public is invited to speak (testify) at any of these hearings and typically, people who testify share their stories and their opinions about how agencies are doing and what they would like to see as a priority in the budget. Agency directors also testify at these hearings to communicate to Councilmembers and the community their own assessment of performance and give updates about the accomplishments and future plans for the agency. These public hearings are particularly important because they have the power to influence funding and priorities in the District!

Performance oversight hearings typically take place in February and March and focus on performance for the previous fiscal year (FY) which covers the time period October 1st through September 30th as well as progress to date in the current FY. After the performance oversight process, the Mayor presents a proposed budget to the Council and budget hearings begin in April and typically end in early May. Once all of the hearings are completed, each Council committee makes changes to the budget based on what they heard from the community. This is called the mark up period. Eventually, the Council will vote to approve a budget that combines all of the work of the committees and this will be submitted to the Mayor, who can then approve or veto the budget. In the event of a veto, the budget is returned to the Council with guidance from the Mayor on what changes may need to be made.

How a Bill Becomes a Law

Remember the example earlier in this guide about how advocacy was used to pass the ADA? That process was part of how the federal government passes laws. The process is similar in the District and the graphic below will walk you through it.

**Council of DC thinks about ideas
for changes in law.**

A bill (proposed law) is introduced by Councilmembers or at the request of the Mayor.

The bill is assigned to a Committee (a smaller group of Councilmembers), based on the subject.

The Committee decides if it will review the bill.

- If not, then the bill dies.
- If yes, then the bill goes to the next step.

The Committee holds a hearing to get comments from the public.

The Committee can:

- Not act and let the bill die;
- Mark up or change the bill;
- Vote the bill out, recommending yes or no.

If a bill gets out of Committee, it goes to the Committee of the Whole (COW), who can put it on on the legislative agenda.

First Reading: The Council debates and can make changes to the bill. The majority can vote to:

- Return the bill to the Committee;
- Say no and the bill dies; or
- Say yes and the bill is scheduled for the next step.

Second Reading: The Council takes a second vote. The majority can vote to:

- Return the bill to the Committee;
- Say no, then the bill dies; or
- Say yes, then the bill passes.

The Mayor can:

- Veto (say no) and return the bill to the Council, which can overrule the veto within 30 days with a 2/3 majority vote; or
- Sign the bill within 10 days, or allow it to become an Act without signing.

The Act goes to the U.S. Congress (House and Senate), where it can:

- Say no, within 30 days (note that this may be longer than 30 calendar days due to Congress' schedule) and with the U.S. President's agreement; or
- Take no action and the Act becomes a law.

Advocacy at each Life Course Stage

The sections below will provide examples of situations that require advocacy throughout the life course. As we know, each stage of life presents new and different challenges and we will learn to tackle them head on! We will follow Barbara and her mother Ms. Jones as they follow Barbara's life course trajectory.

Following the life course examples, we will walk through a case study on the issue of Civil Commitment of people with intellectual and developmental disabilities in the District of Columbia. This case study will provide several strategies for advocacy and help us see how advocacy can make change a reality.

Each life stage is distinct and affects the next stage. In this Guide the life stages are defined as:



Prenatal/Infancy – Early years, often pregnancy and birth to age three



Early Childhood – Preschool age, often defined as age three to five or six



School Age – Everyday life during school years



Transition – Transitioning from school to adult life



Adulthood – Living life as an adult



Aging – Aging and preparing for end of life

Image Description 2: Each life course stage is represented by an image of a different colored circle with white silhouettes of people in the middle of the circle. Prenatal/Infancy is a light blue circle with a baby in the middle. Early childhood is a royal blue circle with three toddlers in the middle. School age is a purple circle with a child wearing a backpack in the middle. Transition is a pink circle with two people wearing graduation gowns in the middle. Adulthood is a green-brown circle with three adults carrying briefcases in the middle. Aging is a yellow circle with two older adults using a cane in the middle. These images will appear on pages 12-20.



Prenatal/Infancy

When Barbara was 18 months old, her mother, Ms. Jones, noticed that she was not walking yet and the other 18 month old children she knew were. Ms. Jones thought her daughter might have a disability and a neighbor told her that she might want to check out early intervention services.

What District agencies and Council of DC Committees work on issues relating to expecting parents and infants with disabilities?

Council Committee	Agency Oversight
Committee on Health and Human Services	Child and Family Services Agency Department of Behavioral Health Department of Health Department of Health Care Finance
Committee on Education	Office of the State Superintendent of Education
Committee on Transportation and the Environment	Department of Parks and Recreation

What are potential system-wide (level 3) issues a family might encounter at this life stage?

- Expanding eligibility for early intervention services
- Mandating that medical professionals make referrals to early intervention when a developmental delay is suspected

What questions will help you advocate for change?

- How is the eligibility of early intervention services determined?
- What systems are in place to connect families of infants with developmental delays to early intervention services?

What questions do YOU have?



Early Childhood

After several developmental assessments, Barbara, who is now two years old, is found to have a developmental disability. At that point, Ms. Jones had heard of early intervention and she contacted the local program, Strong Start.

What District agencies and Council of DC Committees work on issues relating to young children with disabilities?

Council Committee	Agency Oversight
Committee on Health and Human Services	Child and Family Services Agency Department of Behavioral Health Department of Health Department of Health Care Finance
Committee on Education	Office of the State Superintendent of Education District of Columbia Public Schools District of Columbia Public Charter Schools
Committee on Transportation and the Environment	Department of Parks and Recreation

What are potential system-wide (level 3) issues a family might encounter at this life stage?

- Quality and scope of early intervention services
- Transition from early intervention to preschool
- Inclusive preschool programs or recreation programs
- Quality child care for children with disabilities
- Need for peer-to-peer support

What questions will help you advocate for change?

- How is the quality of early intervention services, like physical therapy, speech therapy, and others, evaluated?
- What supports exist to make sure children receiving early intervention transition to an appropriate preschool program?
- Can you tell me about the District's efforts to support inclusion in schools and recreation centers?
- How does the District incorporate accessibility standards into child care center licensing?

- How does the District support initiatives that connect parents and other family members of people with intellectual and developmental disabilities with each other in an effort to provide peer-to-peer supports?

What questions do YOU have?



School Age

When Barbara entered elementary school, Ms. Jones advocated for Barbara to be in a classroom with other children with and without disabilities. Ms. Jones had noticed that there were some classrooms that only contained children with disabilities and she wanted Barbara to have opportunities to learn with children of all abilities.

What District agencies and Council of DC Committees work on issues relating to youth and adolescents with disabilities?

Committee	Agency Oversight
Committee on Health and Human Services	Child and Family Services Agency Department of Behavioral Health Department of Health Department of Health Care Finance
Committee on Education	Office of the State Superintendent of Education District of Columbia Public Schools District of Columbia Public Charter Schools
Committee on Transportation and the Environment	Department of Parks and Recreation

What are potential system-wide (level 3) issues a family might encounter at this life stage?

- Creating inclusive classrooms
- Preventing restraint and seclusion
- Preventing bullying
- Students facilitating their own Individualized Education Plan (IEP) meetings

What questions will help you advocate for change?

- How do the schools determine what the least restrictive environment is for each student?
- How do students with disabilities learn about self-advocacy?
- What laws and policies exist in DC to prevent bullying in the schools?
- How are schools supporting students to learn how to facilitate their own IEP meetings?

What questions do YOU have?



Transition

As Barbara approaches age 18, Ms. Jones begins to worry about Barbara's future as an adult. Ms. Jones advocated for Barbara to receive a diploma instead of a certificate in the hopes that Barbara will have a better chance at getting a job once she graduates. She has gotten connected with the Rehabilitation Services Administration and hopes that they can help Barbara find a job that will make her happy.

What District agencies and Council of DC Committees work on issues relating to youth with disabilities approaching adulthood?

Committee	Agency Oversight
Committee on Health and Human Services	Child and Family Services Agency Department on Disability Services Department of Behavioral Health Department of Health Department of Health Care Finance
Committee on Education	Office of the State Superintendent of Education District of Columbia Public Schools District of Columbia Public Charter Schools
Committee on Transportation and the Environment	Department of Parks and Recreation
Committee on Business, Consumer and Regulatory Affairs	Department of Employment Services

What are potential system-wide (level 3) issues a family might encounter at this life stage?

- Access to post-secondary education
- Quality and coordination of services from the Rehabilitation Services Administration
- Graduating with a diploma or certificate

What questions will help you advocate for change?

- How do DC post-secondary education and career readiness initiatives prepare students with disabilities for higher education or employment and how can they be improved?
- What are the percentages of students with disabilities who graduate with a diploma or a certificate and do potential employers recognize a certificate in the same way as a diploma or GED?

- How does the Rehabilitation Services Administration coordinate with the schools to support students to transition from school to work?

What questions do YOU have?



Adulthood

Barbara graduated at 18 and continued to live with her mother. Barbara wants to live on her own or with a roommate but struggles to figure out how to make this happen. Barbara has been able to find some part-time work, but she does not make enough money to live on her own yet.

What District agencies and Council of DC Committees work on issues relating to adults with disabilities?

Committee	Agency Oversight
Committee on Health and Human Services	Department on Disability Services Department of Behavioral Health Department of Health Department of Health Care Finance
Committee on Housing and Community Development	District of Columbia Office on Aging – Aging and Disability Resource Centers
Committee on Business, Consumer and Regulatory Affairs	Department of Employment Services
Committee on Economic Development	Department of Housing and Community Development

What are potential system-wide (level 3) issues a family might encounter at this life stage?

- Access to recreational activities that are integrated in the community
- Obtaining affordable and accessible housing
- Preferential hiring programs for people with disabilities

What questions will help you advocate for change?

- How do DC recreation centers ensure compliance with the Americans with Disabilities Act?
- What is the District doing to increase the stock of affordable and accessible housing?
- What initiatives exist to incentivize DC government agencies in hiring people with disabilities?

What questions do YOU have?



Aging

Barbara is entering her mid-60s and her mother is now in her 90s. Ms. Jones worries about what will happen to Barbara when she passes away. Barbara has one sibling who lives in another state and who has always been involved in Barbara's life, but also has her own family and job.

What District agencies and Council of DC Committees work on issues relating to older adults with disabilities?

Committee	Agency Oversight
Committee on Health and Human Services	Department on Disability Services Department of Behavioral Health Department of Health Department of Health Care Finance
Committee on Housing and Community Development	District of Columbia Office on Aging – Aging and Disability Resource Centers
Committee on Transportation and the Environment	Department of Parks and Recreation

What are potential system-wide (level 3) issues a family might encounter at this life stage?

- Getting the right support to age at home when family caregivers are no longer able to provide care
- Getting support for decision making while maintaining a right to autonomy

What questions will help you advocate for change?

- How does the District provide in-home services to older adults who live independently and need support?
- What systems are in place for older adults with disabilities to stay active and healthy?
- How does the District support older adults with disabilities to make decisions if they lose the ability to make decisions independently?

What questions do YOU have?

Case Study: Ending Commitment in DC

Is your family member with an intellectual disability going to turn 18? Do you want to make sure that you and your family member will have a say in his or her life as an adult? Do you want to help restore the civil rights of other people with intellectual disabilities in DC? If so, your voice is needed!

The Problem

DC has an outdated law that affects the lives of people with intellectual disabilities and their families. This law, which is over 30 years old, is sometimes referred to as DC law 2-137 and what it means is that people with intellectual disabilities who are labeled by a clinician as having a moderate or profound intellectual disability can be ordered by the court (committed) to receive services from the Department on Disability Services. It also means that any person who is committed must report to the court every year about their health and well-being and the court can issue orders at that time. For example, in the past, the court has issued orders that people lose weight or that they stop having relationships with people the court has decided are not a positive influence on the person.

There is sometimes confusion that this kind of commitment means the person with an intellectual disability is going to an institution. That is what it used to mean when there was a big institution, called Forest Haven, for DC residents with intellectual and development disabilities. However, Forest Haven has been closed for nearly 25 years. The DC service delivery system for people with intellectual disabilities is very different now and is mostly community-based. Despite these changes, the outdated commitment law remains “on the books” in DC.

Commitment takes the power to make life decisions out of the hands of the person and his/her family and gives it to the Court. A person who is committed loses the right to make choices like where to live and with whom; what job, if any, he/she should have where to spend his/her days, and how to spend his/her money. DC is the only place in the country to have this kind of law.

How Can I Make Change?

There is a need for a bill that will end civil commitment for people with moderate to profound intellectual disabilities. Those who know them best – people with disabilities themselves and their families – should get involved in advocacy efforts about the bill. This bill will be important because ending commitment will restore decision-making rights to people with intellectual disabilities, so that they can exercise choices in their lives with the support of their families and other people who know them best. What can you do?

Advocate to Executive Agencies

The **Developmental Disabilities Administration (DDA)** of the **Department of Disability Services (DDS)** is the government agency that manages and funds services to people with intellectual disabilities in DC. It is the agency the Council of DC turns to when thinking about bills that affect people with intellectual disabilities. DDS has made it clear that they are in agreement that commitment should end in the District.

You can advocate at this level by writing a letter or email to let the Director of DDS know how you feel about the bill. You also can work with other parents to set up a meeting with the Director to encourage the agency leadership to continue their support of the bill.

The **State Office of Disability Administration (SODA)** is a sub-agency of DDS. SODA is responsible for engaging the community and reviewing legislation and policy. You can set up a meeting with SODA to let them know you support the bill and suggest any other changes or protections you want to see.



Image Description 3: The logo for the Department on Disability Services shows the letters D-DS in a vertical pattern next to the three red stars and two red stripes of the DC flag sloping upward to the right.

Advocate to the Mayor's Office

The **DC Mayor** has the power to ask for bills to be introduced or to veto (reject) a bill that the Council of DC votes to pass. You can write or make an appointment with the **Office of the Deputy Mayor of Health and Human Services**, who advises and supports the Mayor on issues that include services for people with intellectual disabilities. If the Council of DC or Committee on Health and Human Services rejects a bill, you can ask the Mayor to ask for it to be re-introduced during the next legislative term. Please note that the Committee on Health and Human Services may refer the bill to the Committee on the Judiciary so it is important to find out which Committee will be hearing this bill. The best way to find this information is by calling the Council of DC directly and asking for that information.



Image Description 4: Headshot of Mayor Muriel Bowser smiling and wearing a black suit against a blurred background.

Advocate to the Council of DC and Council Committees

The **Council of DC** creates and passes laws in DC. The Council of DC does much of its work through its committees and in the case of commitment, the Committee on Health and Human Services would be involved with the bill. It will be important to know the Chair of that committee as well as all of the Councilmembers who serve on that committee (current assignments included in the Appendix). You can let these Councilmembers know you want commitment to end in the following ways: by phone, in person or by e-mail/letter.

If you call:

- You can find Councilmember's names and contact information in the appendix of this guide.
- Prepare what you are going to say beforehand.
- Tell the staff person or Councilmember what your "ask" is: An "ask" is what you want the Councilmember to do, like introduce a bill, vote in favor of a bill, make a change to the bill, re-introduce the bill if it dies, etc.
- Let the Councilmember know you will follow up in a week (or sooner, depending on where the bill is in the legislative process) to find out what he or she has done.
- Follow up – by phone and in writing!



Image Description 5: Picture of a white telephone inside an orange speech bubble.

If you meet in person:

- Decide on a purpose (why you are meeting), agenda (what you want to discuss and how), and your "ask"
- Invite supporters to come with you – there is strength in numbers!
- You should first call the Councilmember's office to make an appointment. Let them know your purpose.
- Gather background information for the meeting, including statistics, facts, reports and stories.
- If you plan to share your experiences, practice talking about them ahead of time so that you do not stray off point.
- Prepare a written summary of your points, including your "ask" and contact information. Make sure to give it to the Councilmember or his/her staff at the end of your meeting.
- Keep the meeting brief and always remember your "ask."
- After the meeting, follow up with a thank you note and find out what action the Councilmember took in response to your meeting.



Image Description 6: Two women in black suits shaking hands in front of a table with a coffee mug and notepad on it.

If you email or send a letter:

- Make it personal – tell your story and why you care about the bill.
- Let them know you are a DC resident and a voter. Include your contact information and the ward where you live.
- Tell the Councilmember exactly what you want them to do.
- Ask a specific question that requires a response.
- Follow up with another email, letter, or call if you do not hear back.

Tips for Communicating with Councilmembers

- ✓ You can speak to your ward representative, Councilmember at large or Councilmembers serving on the Committee on Health and Human Services
- ✓ Remember, you may not be able to speak to the Councilmembers themselves, but you can speak to their staff.
- ✓ If you speak to staff, be sure to ask them to pass along your ideas and follow up with a letter or email to the Councilmember to share the staff person's name. Copy the staff person on the correspondence.
- ✓ Let the Councilmembers know if you live in the ward they represent. If not, tell them you are a DC voter.
- ✓ Identify the bill by title and number.
- ✓ Tell the Councilmembers how the bill affects you or your child and what you want them to do - for example, vote for it, re-introduce it, etc.
- ✓ Always be polite, even if you disagree.
- ✓ Thank them and say when you will follow up with them.
- ✓ Tell them you support the bill and why. For example, in the case of the Commitment example, you might talk about the following points:

Talking Point: Once committed, the person usually has to appear in court, before a judge, each and every year – even if he or she doesn't want to!

Talking Point: A person who is committed and their family members lose the right to make choices about their or their family member's life, like where to live, how to spend their days, and how to spend their money!

Talking Point: DC is the only place in the US that still has this outdated law, which does not take individual abilities into account and creates assumptions that all people with a moderate intellectual disability cannot make decisions!

Talking Point: Reform could help you and your family member have more control over how your family gets adult services and supports!

Testify at a Council of DC Hearing

- Sign up to testify by looking the bill up on the Council of DC website and contacting the person listed as the point of contact or ask an allied organization to help you sign up.
- Prepare your speech. You usually will only have 3 minutes, so make sure to get your point across up front.
- You can see, hear, and read previous testimony from hearings to get ideas about how to testify. To watch current or previous testimony, visit the Council of DC website:
<http://dccouncil.us/videos>.

- You can start your testimony by saying your name, why you are testifying, and that you want the Council to vote to pass the bill
- Stay on message
 - When practicing, look at every sentence and ask yourself: “How will this help to pass the bill?”
- Speak from the heart
 - Robert Kennedy, an advocate with Project ACTION! gave powerful testimony for the Developmental Disabilities Reform Act (DDRA) in 2010: “People need to have chances to learn every day, even if they face challenges to learn. If you believe people can learn, they will.”
- Share your story
 - Ricardo Thornton, an advocate with Project ACTION! shared his journey during a hearing for the DDRA in 2010: “There was a time when no one thought me or my wife should make decisions for ourselves. We learned because people opened the door for us and we need to open the door for others and help them show people that they are competent.”
- Use your story to advocate for the whole system to change
 - Rhonda White, a parent of a child with a developmental disability said during her testimony for the DDRA in 2010 that a change in law was needed to: “bring improvement to the lives of the individuals with developmental disabilities and their families to become members of the community who hold and shape their own futures as an integral part of society.”
- Begin and end your testimony with what you want the Council of DC to do.

Attend the Hearing

There is strength in numbers, so showing the Council of DC how many people care about this bill being passed will make a big difference. You can even consider making stickers, buttons, or shirts that show your support for the bill; you should coordinate with other supporters you have recruited and your allies. This lets Councilmembers know there is widespread support for passing the bill.

Find Allies

The Council of DC is one of many resources when fighting for change. You should also make use of your allies. Allies are other organizations and people who want what you want. Some organizational resources in DC include (contact information included in the Appendix):

- Advocates for Justice and Education
- Children’s Law Center
- DC Advocacy Partners
- DC Developmental Disabilities Council
- Family Voices of DC
- Parents Advocacy Leaders Support Group through Health Services for Children with Special Needs
- Project ACTION!
- Quality Trust for Individuals with Disabilities
- University Legal Services

These groups can help you write your testimony, print out your testimony, let you know where and when the hearing is, and answer any questions you may have about the bill. By joining a coalition, you are more likely to find out when actions are being taken on the bill and can have access to more resources on the DC service system and commitment for people with intellectual disabilities.

Vote

Make sure you are registered to vote and make it clear to your Councilmember that you will vote based on this issue.



Image Description 7: Red, white and blue button with black letters that read, "VOTE."

Advocacy is a full-time effort!

Make sure to seek out opportunities to advocate beyond the Council of DC in your social life, at school gatherings, at parent support group meetings, and in opinion articles in a newspaper or newsletter or blog posts. Allied organizations can help by contacting newspapers, locating newsletters or blogs where you could publish, or editing your writing. Keep in mind that your friends and acquaintances may not know about this issue, and they can be powerful allies in this fight. Think about the following actions you can take with members of your community:

- Tell them what is happening and why you think there should be change.
- Educate them about civil commitment for people with intellectual disabilities.
- Encourage them to come with you to talk to the Councilmembers or call their own representatives.
- Ask them to attend the hearing with you to show the Council of DC that lots of people support the bill.
- Start a petition and ask others to sign it, or write a letter to Councilmembers in support of the bill and ask other people to sign it. Anyone can start a petition on the website www.change.org.

This is your chance to tell people why you believe in ending court-commitment for people with intellectual disabilities who are seeking services and supports in DC. Use the points you plan on raising to the Council of DC and your personal experiences in order to connect with those who may not know about civil commitment.

Conclusion

Advocacy is a marathon, not a sprint. And marathons are hard! When we are thinking about and working for system-wide change, we need to be patient and find ways to stay motivated when the change is slow. We need to support each other and keep our vision alive of creating a world where everyone is able to journey toward their goals and dreams. Advocacy is about speaking out and making your voice heard, educating people, showing up, working together with allies and coalitions, developing relationships with decision makers and holding on to a vision for a better District of Columbia and a better world.



Image Description 8: Upper left – A man in a green hat, a white shirt and white plastic gloves as he handles fresh baked bread and smiles. Upper right – A man is sitting in a power wheelchair wearing a white Special Olympics t-shirt and blue shorts with a medal around his neck and a smile on his face. Bottom left – Two people in red jackets have their arms around each other as they blow kisses into the air in front of them. Bottom right – A smiling man is wearing a blue shirt and headphones as he types onto a laptop using one finger.

Human progress is neither automatic nor inevitable... Every step toward the goal of justice requires sacrifice, suffering and struggle; the tireless exertions and passionate concern of dedicated individuals.
~ Martin Luther King, Jr.

Appendix

- List and contact information of DC Government Agencies
- List and contact information of DC Councilmembers and Committees
- List and contact information of the Mayor and Deputy Mayors
- List of agencies that can help people with advocacy
- Sample testimony
- One-page profile template and example

Relevant DC Government Agencies

Child and Family Services

Interim Director: Raymond Davidson
200 I Street, SE, Washington, DC 20003
Phone: (202) 442-6100
Fax: (202) 727-6505
TTY: 711
Email: cfsa@dc.gov
<http://cfsa.dc.gov/>

DC Public Schools

Chancellor: Kaya Henderson
1200 First Street, NE, Washington, DC 20002
Phone: (202) 442-5885
Fax: (202) 442-5026
<http://dcps.dc.gov/DCPS/>

DC Public Charter School Board

Director: Scott Pearson
3333 14th Street NW, Washington, DC 20010
Phone: 202-328-2660
Fax: 202-328-2661
Email: dcpublic@dcpcsb.org
<http://www.dcpccb.org/>

Department of Behavioral Health

Interim Director: Dr. Barbara J. Bazron
64 New York Avenue, NE, 3rd Floor,
Washington, DC 20002
Phone: (202) 673-7440
Fax: (202) 673-3433
TTY: (202) 673-7500
Email: dbh@dc.gov
<http://dbh.dc.gov/>

Department on Disability Services

Director: Laura L. Nuss
1125 15th Street, NW, Washington, DC 20005
Phone: (202) 730-1700
Fax: (202) 730-1843
TTY: (202) 730-1516
Email: dds@dc.gov
<http://dds.dc.gov/>

Department of Health

Director: Dr. LaQuandra S. Nesbitt
899 North Capitol Street, NE, Washington, DC
20002
Phone: (202) 442-5955
Fax: (202) 442-4795
TTY: 711
Email: doh@dc.gov
<http://doh.dc.gov/>

Department of Health Care Finance

Director: Wayne Turnage
441 4th Street, NW, 900S, Washington, DC
20001
Phone: (202) 442-5988
Fax: (202) 442-4790
TTY: 711
Email: dhcf@dc.gov
<http://dhcf.dc.gov/>

Department of Human Services

Director: Laura Zeilinger
64 New York Avenue, NE, 6th Floor,
Washington, DC 20002
Phone: (202) 671-4200
Fax: (202) 671-4326
TTY: 711
Email: dhs@dc.gov
<http://dhs.dc.gov/>

Department of Parks and Recreation

Interim Director: Keith A. Anderson
1250 U Street, NW, Washington, DC 20009
Phone: (202) 673-7647
Fax: (202) 673-2087
TTY: 711
Email: dpr@dc.gov
<http://dpr.dc.gov/>

Department of Youth Rehabilitation Services
Director: Clinton Lacey
450 H Street, NW, Washington, DC 20001
Phone: (202) 576-8175
Fax: (202) 576-8457
TTY: (746) 777-7776
Email: dyrs@dc.gov
<http://dyrs.dc.gov/>

Office on Aging
Director: Dr. John M. Thompson
500 K Street, NE, Washington, DC 20002
Phone: (202) 724-5622
Fax: (202) 724-4979
TTY: (202) 724-8925
Alternate Number: (202) 724-5626
Email: dcoa@dc.gov
<http://dcoa.dc.gov/>

Office of Disability Rights
Interim Director: Alexis Taylor
441 4th Street, NW, Suite 729 North,
Washington, DC 20001
Phone: (202) 724-5055
Fax: (202) 727-9484
TTY: (202) 727-3363
Email: odr@dc.gov
<http://odr.dc.gov/>

Office of the State Superintendent of Education
Interim State Superintendent of Education: Dr.
Amy Maisterra
810 1st Street NE, 9th Floor, Washington, DC
20002
Phone: (202) 727-6436
TTY: 711
Email: osse@dc.gov
<http://osse.dc.gov/>

DC Councilmembers

John A. Wilson Building, 1350 Pennsylvania Avenue NW, Washington, DC 20004

<http://www.dccouncil.us>

Chairperson Phil Mendelson

Office: Suite 504

Tel: (202) 724-8032 | **Fax:** (202) 724-8085

Chair of: Committee of the Whole

<http://dccouncil.us/council/phil-mendelson>

Elissa Silverman

At Large

Office: Suite 408

Tel: (202)-724-7772 | **Fax:** (202)-724-8087

<http://dccouncil.us/council/elissa-silverman>

Anita Bonds

At Large

Office: Suite 110

Tel: (202) 724-8064 | **Fax:** (202) 724-8099

Chair of: Committee on Housing and
Community Development

<http://dccouncil.us/council/anita-bonds>

David Grosso

At Large

Office: Suite 402

Tel: (202) 724-8105 | **Fax:** (202) 724-8071

Chair of: Committee on Education

<http://dccouncil.us/council/david-grosso>

Vincent Orange

At Large

Office: Suite 107

Tel: (202) 724-8174 | **Fax:** (202) 727-8210

Chair of: Committee on Business, Consumer
and Regulatory Affairs

<http://dccouncil.us/council/vincent-orange>

Brianne Naudeau

Represents: Ward 1

Office: Suite 102

Tel: (202) 724-8181 | **Fax:** (202) 724-8109

<http://dccouncil.us/council/brianne-nadeau>

Jack Evans

Represents: Ward 2

Office: Suite 106

Tel: (202) 724-8058 | **Fax:** (202) 724-8023

Chair of: Committee on Finance and Revenue

<http://dccouncil.us/council/jack-evans>

Mary Cheh

Represents: Ward 3

Office: Suite 108

Tel: (202) 724-8062 | **Fax:** (202) 724-8118

Chair of: Committee on Transportation and the
Environment

<http://dccouncil.us/council/mary-m-cheh>

Kenyan McDuffie

Represents: Ward 5

Office: Suite 506

Tel: (202) 724-8028 | **Fax:** (202) 724-8076

Chair of: Committee on the Judiciary

<http://dccouncil.us/council/kenyan-mcduffie>

Charles Allen

Represents: Ward 6

Office: Suite 406

Tel: (202)-724-8072

<http://dccouncil.us/council/charles-allen>

Yvette Alexander

Represents: Ward 7

Office: Suite 404

Tel: (202) 724-8068 | **Fax:** (202) 741-0911

Chair of: Committee on Health and Human
Services

<http://dccouncil.us/council/yvette-alexander>

Relevant Council of DC Committees

John A. Wilson Building, 1350 Pennsylvania Avenue NW, Washington, DC 20004
<http://www.dccouncil.us>

Committee on Business, Consumer and Regulatory Affairs

Chairperson: Vincent Orange

Committee Director: Peter Johnson

Phone: (202) 727-6683

Email: pjohnson@dccouncil.us

<http://dccouncil.us/committees/committee-on-business-consumer-and-regulatory-affairs>

Committee on Education

Chairperson: David Grosso

Committee Director: Christina Henderson

Phone: (202) 724-8060

Email: chenderson@dccouncil.us

<http://dccouncil.us/committees/committee-on-education>

Committee on Health and Human Services

Chairperson: Yvette Alexander

Committee Director: Rayna Smith, Esq.

Phone: (202) 724-8170

Email: rsmith@dccouncil.us

<http://dccouncil.us/committees/committe-on-health-and-human-services>

Committee on Housing and Community Development

Chairperson: Anita Bonds

Committee Director: Irene Kang

Phone: (202) 724-5473

Email: ikang@dccouncil.us

<http://dccouncil.us/committees/committee-on-housing-and-community-development>

Committee on Transportation and the Environment

Chairperson: Mary Cheh

Committee Director: Nicole Rentz

Phone: (202) 724-8062

Email: nrentz@dccouncil.us

<http://dccouncil.us/committees/committee-on-transportation-and-the-environment>

Mayor and Deputy Mayor Contacts

Executive Office of the Mayor

Mayor: Muriel Bowser

John A. Wilson Building

1350 Pennsylvania Avenue, NW, Washington, DC 20004

Phone: (202) 727-2643

TTY: 711

Email: eom@dc.gov

<http://mayor.dc.gov/>

Office of the Deputy Mayor for Health and Human Services

Deputy Mayor: Brenda Donald

1350 Pennsylvania Avenue, NW, Suite 223, Washington, DC 20004

Phone: (202) 727-7973

Fax: (202) 442-5066

TTY: 711

Email: dmhhs@dc.gov

<http://dmhhs.dc.gov/>

Office of the Deputy Mayor for Education

Deputy Mayor: Jennifer Niles

1350 Pennsylvania Avenue, NW, Suite 303, Washington, DC 20004

Phone: (202) 727-3636

Fax: (202) 727-8198

TTY: (776) 777-7776

Email: dme@dc.gov

<http://dme.dc.gov/>

Advocacy Organizations

Advocates for Justice and Education

Phone: (202) 678-8060

Email: information@aje-dc.org

<http://www.aje-dc.org/>

Children's Law Center

Phone: (202) 467-4900

<http://www.childrenslawcenter.org/>

DC Advocacy Partners

Phone: (202) 822-8405 x 132

E-mail: contact@dcpartners.iel.org

<http://dcpartners.iel.org/>

DC Developmental Disabilities Council

Phone: (202) 724-8612

Email: ddc@dc.gov

<http://ddc.dc.gov/>

Family Voices of DC

Phone: (202) 681-7761

Email: d.hodges@familyvoicesofdc.org

<http://www.familyvoices.org/states?id=0052>

Parents Advocacy Leaders Support Group

Phone: (202) 580-6489

Email: cdoggette@hscsn.org

http://www.hscsn-net.org/Parents_Advocacy_Leaders_Group

Project ACTION!

Phone: 202-448-1458

Email: pholton@dcqualitytrust.org

<http://www.dcqualitytrust.org/advocates/join-project-action/>

Quality Trust for Individuals with Disabilities

Phone: (202) 448-1450

Email: info@dcqualitytrust.org

<http://www.dcqualitytrust.org/>

University Legal Services

Phone: (202) 547-0198

<http://www.uls-dc.org/>

Sample Testimony

**Statement of Rhonda White
Before Committee on Human Service
Regarding the Developmental Disabilities Reform Act of 2009
On December 13, 2010**

Thank you Councilman Wells for holding this hearing for the community at large. My name is Rhonda White, a DC resident with a child with developmental delays, and a member of Health Services for Children with Special Needs **Parents, Advocates, Leader (PALS) Support group.**

Today I come as a strong supporter of the DDRA. I speak from the heart as a parent of a beautiful daughter, Trinity, diagnosed with a rare congenital syndrome called Cornelia de Lange Syndrome (CdLS). Through my experiences on this journey, I can shed insight on the need for quality family supports as addressed in the DDRA.

My journey with my daughter started with its valley experiences creating a lifestyle of late nights and early mornings, with intervals of 2-3 hours of sleep. I recall Trinity's projectile vomiting that appeared to be coming from a lifeless body with low weight and loss of hair.

After the initial diagnosis, I was not directed to a central resource in the District of Columbia, but I was handed a stack of papers concerning the characteristics and prognosis of Cornelia de Lange Syndrome.

As I was struggling to manage Trinity's health care needs, I still had to maintain stability in my family with all of my other children. The need to balance and coordinate both medical and educational services placed a strain on my time, my former marriage and my family's financial resources which brought devastating changes to the quality of life for the entire family.

Once early intervention services were finally activated, therapeutic services were often delayed and inconsistent. Then it was time to transition to school. That posed the challenges of locating a school that could support all of her needs and provide an inclusive environment.

As a parent of a child with developmental delays and a Resource Specialist in the disability community, I have experienced and seen the many challenges that families face day-to-day such as....

- delays in the development, finalization and activation of IFSP, IEP, ISP,
- coordination of healthcare and educational needs,

- shortage of therapists and therapeutic services offered according to IFSP, IEP, ISP,
- Lack of trained child care providers for children with special needs,
- Delays in access to much needed equipment and assistive technology

The Family Support Council which is to be developed through the DDRA will provide the supports to address these challenges with a council that should encompass individuals with developmental disabilities, family members and representation of all informed leaders in the disability community.

With the development of the Family Support Council, every need of an infant, child, adolescent, man and woman with a developmental disability will have fair access to an assessment in a timely manner to address their unique needs and how they may be supported through DDRA.

Ultimately, the approval of the DDRA could be a means to bring about the change needed to support the daily and extraordinary needs of each person with developmental disabilities and their family. This will facilitate the empowerment and independence throughout their life spans to help each person become an active and valued participant in their community.

Waiting has occurred for the last thirty years. It must end, so that all services and supports will be offered from a central entity for individuals with developmental disabilities and their families.

Change is inevitable. The approval of DDRA will bring improvement to the lives of the individuals with developmental disabilities and their families to become members of the community who hold and shape their own futures as an integral part of society. Without the DDRA, that change may not occur and that can result in the deterioration of human lives and dreams which will ultimately effect the community's growth in the present and future.

I support the DDRA, so that the District of Columbia, will lead the change, for the lives of individuals with developmental disabilities and their families.

Thank you for your for time and attention to my testimony.

One Page Profile Template and Sample

[INSERT NAME]'s One-Page Profile

What People Like and Admire
about me:

Insert
Photo
Here

What is Important to me:

Supports I Need To Stay Happy, Healthy & Safe:

For a good match: characteristics needed to
be present or absent

Thomas' One Page Profile

What do people like and admire about Thomas?

- Takes good care of his mom
- Taking good care of his home for 16 years
- Advocates for EVERYONE
- Outspoken and stands up for what is right
- Not afraid to call 311 and report something in the community that is not how it should be
- Great bowler
- Not afraid to be who he is
- "He makes me feel more comfortable in my own skin." – Thomas's staff



Supports I need to be the best I can be:

- When my health and mobility issues flare up I need help cleaning myself, cooking, walking and maybe getting to the hospital
- Reading my mail
- Navigating to all my meetings
- Preparing for meetings, I prefer pre-meetings right before the meeting – I need to know what people want me to talk about and what current events are going on so I stay informed
- Finding affordable social activities like theater and movies

Characteristics of people who best support me:

- People who are nice, respectful, don't make judgments and don't think of me as charity work
- Someone who can make healthy food taste good, "I've got taste buds for a reason!"
- Someone willing to be on the go
- People who don't need me to agree with everything they say and who is not going to boss me around
- People who are okay with not being in control, because I am in control
- People who are gay friendly

What is important to me?

- Having control over my life and the way I want to live
- Being involved in my community
- Taking care of my mom
- Being an advocate for people who need help
- Staying informed about current events like political issues and issues that affect people with disabilities
- To be treated with respect
- Nice smelling bath products (coconut, cucumber melon, etc.)
- Going to movies and theater shows
- Being around people I like